

The Effect of Physician Endorsement on Patients' Perceived Importance and Necessity
in Disclosing Genetic Disease to Family

Amanda Harsin, MA

Katy Head, PhD

Indiana University-Purdue University, Indianapolis

The Effect of Physician Endorsement on Patients' Perceived Importance and Necessity in

Disclosing Genetic Disease to Family

When a physician diagnoses a patient with a genetic disease, disclosure to family is an important communication action for both the patient and family. Timely disclosure by the patient to family may help to “activate” [1] family into providing needed support to the patient [2,3], as well as activate individuals in that family to be tested for the disease [4,5,6]. This study examines whether physician endorsement of disclosing a genetic disease diagnosis to family influences patients' perceptions of importance and necessity to disclose to family their diagnosis.

We conducted online surveys with patients (N = 237, Mean age: 54 years; 85.0% Caucasian) diagnosed with a genetic disease called polycystic kidney disease (PKD). The patients in this study are the first person in their family diagnosed with PKD, called the *proband*. Four variables were examined in this study. IVs included participant recall of physician explaining family members' risk for the disease and recall of whether the physician suggested sharing the diagnosis with family. DVs were participant's perceived importance and perceived necessity to disclose diagnosis to family, with each measured on a three-point scale.

Analyses revealed that participants were significantly more likely to think it was important to disclose when the physician explained that family members were at risk and to think it was important to disclose when the physician recommended disclosing the diagnosis to family. Based on these results, physicians should be made aware their endorsement of disclosing to family can significantly increase probands' perceived importance and necessity of talking to their family and that emphasizing the genetic risk for family can increase a patient's perception that it is important and necessary to tell their family.

References

- [1] Greene, J., & Hibbard, J. H. (2012). Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *Journal of general internal medicine*, 27(5), 520-526.
- [2] Peterson, S.K. (2005). The role of the family in genetic testing: Theoretical perspectives, current knowledge, and future directions. *Health Education & Behavior*, 32, 627-639.
- [3] Galvin, K. M., & Grill, L. H. (2009). Opening Up the Conversation on Genetics and Genomics in Families. *Communication yearbook* 33, 33, 213.
- [4] Gaff, C. L., Clarke, A. J., Atkinson, P., Sivell, S., Elwyn, G., Iredale, R., & Edwards, A. (2007). Process and outcome in communication of genetic information within families: a systematic review. *European Journal of Human Genetics*, 15(10), 999-1011.
- [5] Featherstone, K., Atkinson, P. A., Bharadwaj, A., & Clarke, A. J. (2006). *Risky relations: Family, kinship and the new genetics*. Oxford, UK: Berg.
- [6] Weiner, J. L., Silk, K. J., & Parrott, R. L. (2005). Family communication and genetic health: A research note. *The Journal of Family Communication*, 5(4), 313-324.